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## **Being differently the same: an exploration of the mediation of identity tensions in the sharing of illness experiences**

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## **Being differently the same: an exploration of the mediation of identity tensions in the sharing of illness experiences**

### **Abstract**

The sharing of experiences between patients has become increasingly privileged as a source of knowledge and support in contemporary health care. Despite this, relatively little is known about the processes whereby people's experiences become, or fail to become, valued as sources of health-related knowledge in different contexts. Through a secondary analysis of 87 interviews conducted between 2006 and 2008 in the UK with people affected by motor neurone disease (46 interviews) and Parkinson's disease (41 interviews), we explore the identity work involved in turning other people's experiences into 'experiential knowledge' that can be shared between patients. Of particular interest is how the turning of others' experiences into knowledge is presupposed by negotiating a particular type of identity tension – what, drawing on the work of Paul Ricoeur on metaphor, we refer to as 'being differently the same'. We examine the way in which people living with MND and Parkinson's disease spoke of managing this tension as part of the process of accessing and valuing other patients' experiences, both epistemologically and emotionally. Instead of treating others' experiences as a pre-given source of knowledge, we emphasise how experience comes to be embodied and articulated through different media – bodies, speech, text, and images. Moreover, we suggest that paying closer attention to these media provides opportunities for enhancing our understanding of how people with different chronic and/or terminal illnesses use or do not use different forms of peer support – and in particular online ones – as a source of health-related experiential knowledge. Some of the implications of this are discussed in the specific

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context of people diagnosed with incurable neurodegenerative conditions characterised by visible physical deterioration and associated emotional distress.

**Keywords:** United Kingdom; Motor Neurone Disease; Parkinson's disease; identity tensions; metaphor; illness experiences; experiential knowledge; secondary analysis.

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## **Introduction**

The idea that experiential knowledge – defined as ‘truth based on personal experience with a phenomenon’ (Borkman, 1976, p.445) – can be a valuable resource in health care was initially promulgated by the self-help movement during the 1970s. Today, patients’ experiences, and the sharing of these experiences, are well recognised as a source of knowledge and support in healthcare decision-making and practice (Abel & Browner, 1998; Lawton, 2003; d’Agincourt-Canning, 2005; Etchegary et al., 2008; Locock & Brown, 2010; France et al., 2011).

Research into the health implications of experiential information-sharing has been carried out from a range of disciplinary perspectives, most notably the medical and nursing sciences, psychology, and sociology. Researchers working within this multidisciplinary space define what counts as a ‘patient experience’ by drawing on their respective disciplinary repertoires. From a sociological perspective, patient experiences are not treated simply as expressions of internal individual ‘truths’, even though the experiences in question may indeed be considered ‘true’ by the person expressing them. Instead, different aspects of the construction(s), dissemination(s) and meaning(s) of patient experiences are explored, such that the socially contingent dimensions of what counts as ‘experience’ are brought to the fore. This includes, for example, analyses of the role that experience, in the form of narrative storytelling, plays in constructing and re-constructing identities and subjectivities (Williams, 1984; Frank, 1995; Bury, 2001), or explorations of the connections between the construction of patients’ experiences and the use of particular media sources and imagery in different contexts (Kitzinger, 2000; Seale, 2003).

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One platform for the sharing of experiences that has received particular attention is the internet (Drentea & Moren-Cross, 2005; Winefield, 2006; Coulson et al., 2007; Bar-Lev, 2008; Armstrong & Powell, 2009; Mo & Coulson, 2010). The growing body of work on how people use the internet to share experiences of different health conditions has largely followed two avenues of analysis: the question of how experiences are *(re)presented* online; and the issue of how to measure the various *effects* of the sharing these experiences. In this paper, however, we explore something else – namely, the mechanisms whereby patients turn other patients' experiences into a source of knowledge and support, an issue that is often tacitly implied in the above two dominant analytical perspectives, but rarely explicitly discussed.

Drawing on a secondary analysis of 87 narrative interviews with people living with two neurodegenerative conditions – motor neurone disease (MND) and Parkinson's disease (Parkinson's) – we suggest that in order for *other patients' experiences* to be deemed meaningful, be it psychologically (for example, in terms of emotional support and understanding) or practically (for example, in terms of sharing useful advice), the person receiving the information must identify with the person providing it. In the health context, this sense of identification is typically premised on the existence of a common diagnosis. However, while this identification underpins a great deal of the epistemic and emotional value attributed to other people's experiences, it can, at the same time, be a source of emotional distress, resulting in certain tensions in identity in which people resist cultivating 'disease' identities (Locock & Brown, 2010). Building on this, we explore some aspects of

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the *identity work* that takes place in order to turn other people's experiences into epistemologically meaningful and emotionally manageable sources of knowledge.

The paper is structured as follows. First we provide a brief introduction to MND and Parkinson's disease. Next we outline the methods we used in some detail. Our findings form the main body of the discussion and are broken into three sections. First, we examine tensions of identity in peer support in general and the sharing of experiences in particular. Second, we develop the concept of 'being differently the same'. Third, we turn our attention specifically to the internet and to broader questions of mediation in the sharing of experience. In conclusion, these three areas of analysis are drawn together and their implications discussed in relation to the concept of metaphor and the role of experiential knowledge in health care.

## **MND and Parkinson's disease**

MND and Parkinson's are neurological conditions characterised by the progressive degeneration of nerve cells and unpredictable prognoses (McDermott & Shaw, 2008; Tsouli & Konitsiotis, 2010). Both conditions typically, although by no means invariably, affect people over the age of 40. Parkinson's has an estimated prevalence of about 0.2% (approximately 200 people out of 100,000) in the general population (Clarke, 2007), whereas MND is rarer, with an estimated 7 out of 100,000 people living with the condition in any given year (<http://www.mndassociation.org>).

While neither condition is curable, the progression of MND is often very rapid and has been described as straddling the terminal and chronic categories (Brown, 2003). In its most

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prevalent form – amyotrophic lateral sclerosis (ALS) – MND presents in both upper and lower motor neurones. When the onset of the disease is experienced in the form of limb weakness, patients are expected to live between two to five years. When the first symptoms of the disease are experienced in the throat or mouth – bulbar onset – the deterioration is faster and life expectancy may be as short as a few months. The speed of deterioration is very hard to predict and there are two slower progressing variants of MND – primary lateral sclerosis (PLS) and progressive muscular atrophy (PMA). A diagnosis with MND has been described as an ‘existential shock’ (Brown, 2003), which can result in a process of ‘biographical abruption’ (Locock et al., 2009).

In addition to the psychological distress associated with a diagnosis of MND or Parkinson’s, patients have to deal with unpredictable, visibly noticeable and seriously debilitating, symptoms. In the case of MND these include the loss of the ability to walk, talk, eat, drink or breathe (Brown, 2003). The main symptoms of Parkinson’s are shaking, stiffness, slowness and difficulty with movement, while later symptoms can include postural instability, dizzy spells and dementia (Clarke, 2007). A range of treatments are available for Parkinson’s and in most cases deterioration is slower and less visibly noticeable than in MND. Thus, unlike MND, Parkinson’s can more straightforwardly be considered a chronic condition.

## **Methods**

This paper is based on a secondary analysis of pre-existing qualitative interviews carried out with people affected by MND and Parkinson’s (Heaton, 2004). All the interviews were collected by the University of Oxford’s Health Experiences Research Group. Ethical approval



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for secondary data sharing and analysis had been received from the Eastern Multi-Centre Research Ethics Committee (ref: 03/05/016). The interviews were collected using maximum variation sampling, with variation across demographic variables and type of experience (Coyne, 1997).

The interviews are in-depth narrative ones, conducted with a view to soliciting experiences of illness across a range of topics. In the first half of the interview participants were invited to tell their story for as long as they wanted with as little interruption as possible. In the second half, a semi-structured interviewing approach was adopted to enquire after topics of interest that had not already been raised and to explore key topics in more depth. The interviews were carried out by three primary researchers: researcher one conducted interviews with people affected by MND; researcher two conducted interviews across the MND and Parkinson's modules; researcher three conducted interviews with people affected by Parkinson's. Since the interviews were collected as part of one programme of work, the same topic guide was used throughout. The majority of the interviews lasted between one and two hours. All interviews were video or audio-recorded and transcribed verbatim. Pseudonyms are used to protect the anonymity of participants.

The work presented here was carried out in order to inform a National Institute for Health Research (NIHR) funded programme of work on the practices and implications of the online sharing of health-related experiences. The overall aim of the secondary analysis was to conduct a 'supra-analysis' on this topic (an analysis in which the data is analysed from a new theoretical perspective (Heaton, 2000)). As one of the authors (LL) carried out roughly half

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of the interviews with people affected by MND and has published papers based on them (Locock et al., 2009, Locock & Brown, 2010), the present paper can also be considered, in part, a 'personal or inside secondary analysis' (Heaton, 2004, p.12). For a detailed discussion on some of the challenges and opportunities afforded by secondary analysis see Heaton (2004); for an in-depth discussion of the process of carrying out a secondary analysis on some of the same interviews see Locock and Brown (2010).

In the first round of coding, which included 46 interviews with people affected by MND (35 patients and 11 carers) and 41 interviews with people affected by Parkinson's (37 patients and 4 carers) living in the UK, the transcripts were read and coded with a dual focus: the topic of sharing experiences with other patients (face-to-face and online); and the topic of internet use in general. To contextualise this analysis, a website that provides summaries and descriptions of these interviews for the public (<http://www.healthtalkonline.org>), was reviewed; the interviews were read and coded thematically in their entirety in conjunction with brief biographies of the interview participants.

Although the interviews did not focus exclusively on issues pertaining to the sharing of illness experiences, this was a recurring topic of interest, broached by interviewers and interviewees alike. Consequently, there was a great deal of material across the interviews on people's perceptions and practices of peer support. There was significant overlap between the themes that emerged in relation to sharing experiences across both conditions, seven of which were particularly prominent: 1) 'Seeing' famous people with the condition on television, websites, books, and hearing or reading about their experiences; 2) The tension between

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citing the utility of other people's experiences and reporting negative emotional responses to seeing these others (including fear, anxiety, depression and despair); 3) Valuing others' experiences because they were (potentially) the same as one's own, yet emphasising that everyone's experiences were different; 4) Attitudes to peer support changing over time; 5) Citing one's type of 'personality' as a reason for wanting to engage in peer support *and/or* not engaging in it; 6) Identity tensions when associating with and/or being associated with a disease; 7) Differences between the different media through which 'experience' is communicated.

During this coding process we were struck by the way that interviewees' spoke of how *seeing* other people with the same condition as them influenced their perspectives on the above themes. We decided to include 'seeing others' as an emergent category across both conditions and, drawing on a modified version of some of the practices advocated in grounded theory, we did further thematic coding using a constant comparison approach on this specific theme (Charmaz, 1990). When we coded specifically for 'seeing others', an ambivalence emerged: interviewees often expressed an aversion towards *seeing* others with the same condition, yet, at the same time, said that being in communication with and sharing experiences with these people had both emotional and practical benefits for them.

In the first round of coding we had already noted a strong thread of ambivalence running through people's perceptions of seeking out and sharing experiences, expressed in terms of a tension between hope and fear, similarity and difference. In our second round of coding this ambivalence was explicitly linked to the *visual* engagement implied in sharing experiences.

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In the MND interviews with which we started the analysis, 'seeing others' was often expressed as extremely upsetting – as needing to be managed or even outright avoided, in order to benefit from their experiential knowledge. Thus, we decided to focus on this 'visual' ambivalence and code whether people spoke of 'seeing others' in primarily positive, negative, ambivalent (positive and negative), or neutral terms.

Without quantifying our data inappropriately or drawing misleading generalisations from it, we found that a similar proportion of interviewees in the MND and Parkinson's modules discussed 'seeing others' in some depth. However, this tended to be articulated in more strongly negative or ambivalent terms in the MND interviews (coded at approximately 82% of those who spoke of 'seeing others') than in the Parkinson's interviews (coded at approximately 43% of those who spoke of 'seeing others'). While we are not suggesting that this pattern can or should be seen as generalizable, it does raise questions as to why this was so and whether these, or similar, patterns are present in perceptions of peer support in other health conditions.

The differences we noted are, of course, influenced by a number of factors, including methodological ones (such as variations in primary researcher interview style and our coding methods) and contextual ones (such as differences in the types of peer support available and contemporary media coverage of the conditions). While it is not our intention to draw comparisons between these two groups, based on our analysis, we propose the tentative hypothesis that these differences relate, in part, to variations in both the visibility *and* severity of symptoms. We suggest that this raises further questions concerning how the practices and

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implications of peer support more generally, and the sharing of experiences specifically, differ in relation to conditions with different symptoms and prognoses. Moreover, as will become clearer in what follows, it prompts further comparative research on how patients' experiences are mediated and valued differently, not only in relation to different health conditions, but over time and in relation to different media and technologies.

Selecting what themes to focus on and which interviews to quote directly was a difficult task. For the sake of brevity, we have selected quotes that spoke about 'seeing others' and the tensions of identity this entailed in a concise manner (for example, we avoided cases where this was discussed over multiple paragraphs). As we cannot, unfortunately, cover the entire range of perspectives contained in the interviews, we have selected quotes that we believe best illustrate the ambivalence discussed above, while, at the same time, trying to represent as many interviewees as possible.

### **Tensions of identity, peer support and 'seeing others'**

In the UK people diagnosed with MND often take part in and value peer support provided through the MND Association (the main MND voluntary organisation) and other channels. This includes face-to-face support groups, home visits, reading about other people's experiences on websites, and the use of online forums. Two online forums, in particular, were frequently mentioned in interviews: BUILD ([www.build-uk.net](http://www.build-uk.net)) and PatientsLikeMe ([www.patientslikeme.com](http://www.patientslikeme.com)).

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The use of peer support services by people affected by MND has been discussed in some depth in previous research (Locock & Brown, 2010). In this work peer support has been highlighted as a source of practical advice as well as providing a sense of camaraderie and opportunities for social comparison. The authors also note that choosing *not* to take part in peer support activities and avoiding meeting other people with MND can be a deliberate defensive strategy aimed at protecting oneself from seeing one's possible future. In addition, they discuss how some MND patients felt a certain '*tension of identity*' in being identified, as well as in identifying themselves, as 'a person with MND, rather than the person I am that happens to have MND' (Locock & Brown, 2010, p.1504).

In the present paper, instead of focussing on issues pertaining to social comparison, we examine how people living with MND and Parkinson's spoke of negotiating the difficulties and benefits of meeting others affected by the same condition as them in more detail. What has emerged from our analysis of this is that even amongst those patients who attended group meetings and were actively involved in patient organisations, *seeing* other people with the same condition was often expressed as having been a particularly potent source of distress at some time or other:

Surrounded by patients at the hospital in various stages of incapacity suddenly made me fear that I could be like them within two years. My husband and I went home on the train in a state of total shock and dread for what lay ahead. (Angela)

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We went to this lunch, and what did it do for me? All right, I met other people who have motor neurone disease. Do I really want to do that? Because there were people there who were quite badly affected. Do I really want to see what I could end up like, and have everyone patting each other on the back? (Brenda)

I know the worst scenario, I mean I've seen the people on the television and I just hope, dear God, that isn't me. (Anna)

The excerpts above show how three different people with MND spoke of their reactions to seeing other people with the same diagnosis. Although in each case these 'other' people with MND are seen in different contexts – in a hospital, in a group meeting, and on television, respectively – the interviewees' responses to the visible signs of physical deterioration in others are expressed as highly upsetting. What is at stake here, however, is not simply the expressions of psychological distress, but the manner in which this distress is entwined with a particular sense of identification: *'I could be like them within two years'*; *'see what I could end up like'*; *'I just hope, dear God, that isn't me'*. It is not just that these 'others' looked physically unwell and that the interviewees were upset as a consequence of empathising with them or comparing themselves to those they perceived as worse off than themselves – a mechanism sometimes referred to as negative 'downward social comparison' (Festinger, 1954). Rather, interviewees were distressed because they saw *their own* future selves reflected in these others; they were, at some level, perceived and seen as *the same as them* due to their shared diagnosis.

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This sense of identification (and distress) was expressed not only in the interviews with people affected by MND, but also those affected by Parkinson's:

When we were coming out of the, [um] of the consulting room and seeing the next man, he was about to come in. And, and he was writhing around in a, in a wheelchair and he had terrible dyskinaesthesia which is this sort of writhing movement which you can see me doing a bit now. I'm rolling a bit from side to side. But his was far, far worse and his tongue was out and it was sort of. It was, he seemed to be sort of writhing around like a snake, like a, and he didn't have any control of his, his motion at all. And I thought, 'God this is awful. How, how long is it going to be until I am like that?' (Andrew)

Yet, upsetting as this identification may be for some people in some instances, it is at the same time one of the principal reasons why the sharing of experiential information is valued so highly by patients – as reflected in the name of the popular website *patientslikeme* ([www.patientslikeme.com](http://www.patientslikeme.com)). Indeed, many of the potential positive effects of this identification have been discussed in relation to peer support and internet use. They include, for example, creating a sense of communality and belonging (Sharf, 1997; Steffen, 1997; Gavin et al., 2008; van Uden-Kraan et al., 2008), comparing and validating knowledge and information (Armstrong & Powell, 2009; Locock & Brown, 2010), facilitating the exchange of practical tips and advice (Steffen, 1997; Sandaunet, 2008; van Uden-Kraan et al., 2008), enabling normalisation and expectation management (Harvey et al., 2007; Lowe et al., 2009).

However, our analysis suggests that a fundamental tension underlies these practices and their consequences. In order for other patients' experiences to be meaningful and for the sharing of



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these experiences to perform the positive psychological and practical outcomes attributed to them, the patients in question need to *identify* with each other – they need to perceive themselves as being, at some level, ‘the same’. And yet, identifying with someone who is manifesting the physical symptoms of a debilitating and incurable disease that one is also diagnosed with is highly upsetting. This, we suggest, results in an identity tension that needs to be negotiated in order for patients to be able to engage and benefit from experiential information sharing.

### **The importance of being differently the same**

As discussed above, interviewees frequently explained that the reason they felt an aversion towards seeing other people with the same condition as them was that this reflected their possible future deterioration. In many cases, however, an initial reluctance to engage in peer support subsided over time and interviewees spoke of how they overcame the resistance they felt towards seeing and meeting others with the same diagnosis once they started attending support groups.

In addition to perceptions about peer support changing over time, in many of the same interviews where participants spoke of seeing their future selves in others, they also stressed that everyone was *different*. Indeed, in two of the interviews from which the MND-related excerpts presented earlier were taken (those with Angela and Anna), interviewees emphasised that everyone with MND was ‘different’ and that simply having the same diagnosis was *not* an adequate basis for an automatic association. Yet, despite this, both interviewees said they still preferred *not* to see other people with MND, because of a potentially upsetting similarity.

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Interestingly, in a number of interviews attention was drawn, either explicitly or implicitly, to the fact that the sense of distress interviewees felt in response to seeing other people with serious health conditions emerged specifically in relation to other people with the *same* diagnosis as them. For example, later in her interview, when Anna was asked if she had any advice to give to other patients, she explicitly advised going to a hospice to see how other people coped with illness:

Go to a hospice and then you'll damn soon see how lucky you are. When you see young people struggling with their health for the hospice and staying alive and that's when it gives you a good jolt and makes you realise how lucky you are.

Although this might seem to contradict some of her earlier statements in which she spoke of being distressed by seeing other people with MND and specifically avoiding a man with MND who attended the same hospice as her, in this last excerpt Anna is not referring to patients who, like her, have MND. Moreover, she does not speak about identifying with them in the same way as she does with the people living with MND that she has seen on television, about whom she said: *'I just hope, dear God, that isn't me'*.

Similarly, other interviewees, such as an occupational therapist, a speech therapist, a participant with experiences of MND in the family, and another who had been involved in voluntary care work, were quite familiar with serious illness. Yet, still they expressed an initial hesitation regarding meeting other people with MND post their own diagnosis. In such

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cases interviewees regularly invoked difference as a means of negotiating their interaction with people diagnosed with the same condition as them. In fact, recognition of how people living with the same condition were both different and the same – *differently the same* – was one of the primary ways interviewees spoke about overcoming their initial resistance to seeing and sharing their experiences with other people living with MND:

We both summoned up our courage and, and went to a meeting. [um] And it took two or three meetings I, [um] I suppose really to begin to feel comfortable meeting other people with MND, [um] realising that it, it strikes everybody so differently and seeing somebody does not necessarily mean that's how you're going to be in a few months' time. (Jenny)

Having said that one of the branches has at least two people who are [um] in the same situation I'm in. So, well just proves we're all different and you can't make, shouldn't make generalisations. (Harry)

Yes, well I would advise anyone to go to group, again we're all different, I mean I've, I'm a member of a, a support group at the local hospice to which my wife and I both went and I, I enjoy my time at the hospice but some people well didn't survive and some people who have been discharged just don't go back. (Philip)

This same reasoning was also prevalent in the Parkinson's interviews:

It's a bit difficult saying to people to talk to other people with Parkinson's, because there's, as we said a minute ago, Parkinson's is so different, it has different manifestations with

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everybody. (Lucy)

And that's the other funny thing about Parkinson's that it's, it's very individualistic. Not everybody has the same symptoms whereas lots of other diseases the symptoms are very, very similar and you can go straight from the symptoms to specific diagnosis. Whereas with Parkinson's, the symptoms vary tremendously from one person to another, and the combination of symptoms that people have vary tremendously. (Bruce)

While discussions on the value of sharing experiential information are usually premised on the expectation of an underlying similarity in patients' experiences the role that difference plays in these interactions has rarely been developed. Here, we suggest that the cultivation of a sense of *difference in similarity* plays a crucial role in resolving the tensions discussed in the preceding section. What is more, rather than the tension between similarity and difference being a 'problem' – such that, in order for the epistemic value of experiential information to be increased, it needs to be resolved – we suggest it plays a fundamental role in how others' experiences are turned into a source of knowledge in some chronic (and in the case of MND sometimes terminal) illnesses. Thus, we suggest that *being differently the same* not only describes a particular way of negotiating this tension, but forms an important part of the constitution of experience *as* knowledge.

## **Mediating experience**

In the previous section we discussed how people living with MND and Parkinson's negotiate similarity and difference as a means of managing their engagement with other people with the same condition as them. However, rather than similarity and difference being fixed

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categories, they are spoken of as temporally and situationally contingent. At some stages, participants highlighted a shared embodiment of the same condition as the primary reason why they valued others' experiences, yet, at other times, they said that others' experiences were irrelevant because, after all, everyone is different.

An important way in which people spoke of managing their sense of identification with others was through being selective about the communications media through which they associated with them. In order to illustrate the bearing that different communications media have in relation to turning experiences into a knowledge resource, we will draw on two cases taken from interviews with two people with MND, first Brian and then Carol. Below Brian speaks about using an e-mail forum:

Interviewer: Mm, mm. [um] Have you been to any support group meetings and met other people with the condition?

Brian: [um] I did have a look on the Motor Neurone Disease page, where you actually chat to like people with the disease, but some people I couldn't bear to look because of their condition. So I just . . .

Interviewer: Was this the, the Build email forum?

Brian: Yeah, yeah.

Interviewer: Yeah.

Brian: Yeah. Because you're talking to like people and then they send you pictures as well. And it's just too much to take in, because then it's all in your mind then, 'Oh, God,' you think, 'this is going to happen here, this is going to

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happen.' I think I just turned it off. [laughs]

Interviewer: Mm. So you'd rather not –

Brian: No.

Interviewer: – meet up with people in person at a –

Brian: No.

Interviewer: – support group meeting or anything?

Brian: No. I mean, I don't mind talking to them over the phone, which is available, I know. But then I think seeing someone is totally different.

In the excerpt above Brian expresses a similar aversion to seeing other people with MND as that discussed in the first section: '*this is going to happen here, this is going to happen*'. Yet, rather than employing difference as a means of mitigating his sense of identification with other people with MND, he focuses on the medium of communication. Brian highlights how talking to another person living with MND over the phone is '*totally different*' to seeing them.

Indeed, Brian's initial problem with the online forum had to do with users sending in their pictures. The relevance of *vision* as a particular mode of communicating experience came up frequently in interviews, with some people, such as Brian, preferring not to see other people with MND and being more comfortable communicating through another medium, such as the telephone. Thus, the medium through which experiences were articulated and shared – be it through text, image, voice or bodies – was crucial to how they were appropriated. In

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mediating how the experience of MND is communicated, Brian alters both the type of the experiential knowledge he receives and the manner in which he identifies with other people living with MND. While the source may be the same and its validity still rests on it being the 'embodied' experience of someone else living with MND, the meaning these experiences hold and Brian's response to them differs considerably depending on the form these 'embodied' experiences are communicated through.

Significantly, interviewees often seemed to turn specifically to the internet as a medium for sharing experiences precisely because they perceived it as allowing them to be more in control of and selective about their mode of communication, both physically and emotionally (which does not mean, of course, that selection and control is always guaranteed, as is evident in Brian's example above). In addition to the internet being used as a means for controlling the mode of communication through which experience is articulated and shared, it was also seen as a means for maintaining a certain distance that, in fact, allowed the sharing of experiences with other patients. This is illustrated by the excerpt from the interview with Carol, where she discussed her use of the same forum that Brian referred to:

And also it's a, it's a two-way thing. It's quite worrying. You like the support you have helping one another but you're scared that, I think, well I'm personally scared that if I met up with someone face-to-face and we started meeting up that if they needed to become reliant on me or to talk to me about their problems with MND that I wouldn't be strong enough for that. I mean it might not be the case that they would do that but you don't know. So I think too. I like having the e-mail contact but I don't

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think I would want personal contact with someone else with MND because I think it gets too involved then. [um] Often on UK BUILD you'll find someone else who's just died who was a regular contributor and that's really upsetting. And that's just knowing them from talking to them on the website so I think it would be even more disturbing if you actually built up a closer relationship with someone. So I keep my distance a bit.

Rather than the internet being a substitute for the face-to-face sharing of experiences, Carol expresses it as preferential. One of the reasons Carol gives for this preference is that she feels her use of online forums allows her to foster a sense of distance in her communication with other people living with MND: '*So I keep my distance a bit.*' What is particularly interesting about the distance described here is that it is precisely by reducing her interaction with other people living with MND to e-mail that Carol feels able to develop a form of information exchange that she finds manageable. 'Distance' in this case is not the antithesis of empathy, but precisely that which enables particular forms of computer-mediated distal empathy.

In the above excerpts from interviews with Brian and Carol, both of them, albeit in different ways, emphasise that the mediation of other people's experiences plays an important role in how these experiences are shared and appropriated.

## **Discussion and conclusion**

Research on 'patients' experiences' and 'experiential knowledge' is far from new. However, despite a sociological emphasis on the constructed and contingent nature of knowledge



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claims, barring a few exceptions (Abel & Browner, 1998; d'Agincourt-Canning, 2005; Etchegary et al., 2008; France et al., 2011), there has been relatively little interrogation into the processes through which patients' experiences become (or fail to become) valued as sources of knowledge and support in different healthcare contexts. Yet, as patients' experiences are being accorded an increasingly central position within a broader emphasis on patient choice, participation and expertise in healthcare policy and service delivery in the UK and elsewhere, this situation is no longer tenable. For examples of this in NHS policy see Department of Health (1998, 1999, 2001, 2010); for discussions on this trend more generally see Arksey (1994), Church et al. (2002), Martin (2008) and Mol (2008).

In this paper we have contributed to the broader literature on the sharing of illness experiences through developing a dual emphasis on the epistemic implications of *being differently the same* in the sharing of experiences and the mediating role of communications technologies in this. In our analysis of interviews carried out with people affected by MND and Parkinson's, two ways of making the sharing of experiences epistemologically meaningful *and* emotionally manageable emerged as particularly prevalent. First, in addition to emphasising *similarities* based on a common diagnosis as a major reason for valuing other's experiences as knowledge (a well-accepted cornerstone of peer support), interviewees regularly brought up similarities *in concurrence with differences*. Second, interviewees spoke of using *different media and ways of sharing experiences* as a means of managing their identification with other people diagnosed with the same condition as them.

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The emphasis interviewees placed on similarity and difference echoes the distinction that has been made between 'embodied' and 'empathetic' experiential knowledge (Abel & Browner, 1998). While Abel and Browner do not suggest that these two categories are mutually exclusive, they differentiate between the former as knowledge generated through one's own bodily experiences and the latter as knowledge generated through caring for or being close to someone. Building on this here, we have suggested that the epistemic validity of other people's experiences as a source of knowledge in the context of peer support is premised, crucially, on managing the *simultaneously* embodied and empathetic dimensions of experiential knowledge. Indeed, others' experiences would not be considered knowledge if they were not deemed, in some way, as an empathetic (shared) embodiment of a particular condition.

Furthermore, we have drawn attention to the risk of conflating experiential knowledge with verbal (oral or written) media alone. Instead, in certain conditions, especially those where the effects of the disease are visible, people's *bodies* serve as important vehicles for the articulation of experience, which means that the *visibility* of patients' bodies plays a significant role in the sharing of experiences. This, we argue, must be taken into account when analysing how different experiences are articulated and identifications managed in different contexts and media of communication, including the internet.

While 'empathetic knowledge' has been broken down further into 'vivid' versus 'vague' (Etchegary et al., 2008), our analysis suggests that the 'vividness' of other people's experiences is much more than simply a matter of information presentation or individual

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recollection. What counts as the most 'vivid' and effective medium for communicating experience in a given context emerges as part of a complex network in which the embodiment and articulation of experience is entangled both with how it is mediated *and* its affective dimensions. Thus, we suggest that additional theoretical and comparative work that conceptualises how 'experience' is turned into different forms of knowledge in health care is needed.

A key contribution of this paper is a foregrounding of the *epistemic* significance of *identification* in peer support. We suggest that the on-going exploration of this has the possibility to open up opportunities for deepening our understanding of new modes of knowledge and ways of knowing emerging in the sharing of illness experiences in contemporary health care. A particularly promising avenue for further conceptualising the identity tension we have referred to as *being differently the same* is its connection with Paul Ricoeur's theory of metaphor (Ricoeur, 2003 [1977]).

The use of metaphor has been studied extensively in the context of various diseases and chronic illnesses, including HIV/AIDS (Clatts & Mutchler, 1989; Sontag, 1989; Patton 1990; Weiss, 1997; Treichler, 1999), cancer (Sontag, 1977; Seale, 2001; Gibbs & Franks, 2002; Clarke & Everest, 2006), Ebola (Ungar, 1998; Joffe & Haarhoff, 2002), and SARS (Wallis & Nerlich, 2005). These studies have typically focussed on analysing the metaphoric elements of illness *discourses*, such as those contained in patient narratives, media representations of health and illness, and healthcare policy. Although this work has considerably broadened our appreciation of the implications of metaphoric language (including its role in related

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practices), it is nonetheless built on an understanding of metaphor as a particular form of figurative representation, albeit one with wider cultural, experiential and political significance.

In this paper, however, our interest in metaphor is quite different. Instead of dissecting specific metaphors and analysing their rhetorical, representational or strategic use in particular discourses and practices, we wish to highlight the salience of a particular relation that lies at the conceptual core of metaphor. Metaphor is interesting not just as a rhetorical device or figure of speech, but as the embodiment of a particular identity tension. Put differently, metaphor offers a distinct way of expressing relations between similarity and difference. Indeed, according to Paul Ricoeur, at the heart of the concept of metaphor lies a paradox: 'in metaphor, "the same" operates *in spite of* "the different"' (Ricoeur, 2003, p.232). In other words, in metaphor similarity and difference are not simply conjoined, but are also at the same time always opposed. Similarly, in the analysis presented in this paper, the attribution of epistemic value to other people's experiences was presupposed by a particular type of identity tension: being simultaneously the 'same as' and yet 'different from' other people diagnosed with the 'same' condition.

A great deal of the extant work on the use of metaphor in health-related contexts draws inspiration from Lakoff and Johnson's seminal work *Metaphors We Live By* (Lakoff & Johnson, 2003 [1981]), which defines metaphor very broadly as 'understanding and experiencing one kind of thing in terms of another' (Lakoff & Johnson, 2003, p.5). In this paper we suggest that such a definition neglects to highlight the crucial role played by

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*difference* in these relations. By contrast, Ricoeur's theory of metaphor provides a more useful theoretical toolbox for examining the crucial, yet under-examined, role that negotiations around *difference in similarity* play in the turning of others' experiences into knowledge in peer support.

This paper raises a number of questions that we hope shall be tackled by future research: Do the patterns described here emerge in relation to other health conditions? How do the visibility of symptoms, the rate of physical deterioration, and the unpredictability of a disease shape how, what, why and where experiences are or are not turned into knowledge in health care? What roles do different media and modes of articulation, online or otherwise, play in this? How might we conceptualise the epistemic dimensions of experience most appropriately? What role might the alternative understanding of metaphor presented here play in this? And, perhaps most importantly, what are the consequences of the appropriation of experience as knowledge on people's healthcare-related perceptions and practices?

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